Short Report to Steering Committee

From Best Practice Committee

Statement for Determining Best Practice:

The National Research Council stated that while some intervention strategies for individuals with Autism Spectrum Disorder (ASD) have been developed and scientifically demonstrated successful, no single intervention or approach has proved to be effective for every individual with ASD. Successful programs are developed and interventions chosen by using the following process:

1. A thorough and professional evaluation of the individual's strengths and needs is conducted.

2. A meaningful plan is developed with the individual's and family involvement at every phase.

3. Meaningful goals and objectives must be developed based on the individual with ASD and family input.

4. An individual's interventions are implemented through a thoughtful, comprehensive plan that provides structured learning opportunities.

5. Outcomes of programs and interventions are evaluated frequently leading to continuation, discontinuation, or revision.

Guiding Values in providing best practices:

1. Assure resources are not limited by geography/funding
2. Provide intervention/treatment as soon as possible
       (as soon as ASD diagnosis is seriously considered)
3. Provide treatment through lifespan and across all settings
4. Respect and listen to individuals with ASD and their families; incorporate their values and beliefs
5. Ensure coordination of care through cohesiveness, collaboration and clear communication between all services provided to individuals with ASD and families across settings
6. Keep individuals with ASD safe
7. Provide quality pre-service, in-service training and ongoing mentorships to professionals, individuals with ASD and their families

Recommended Processes

1. Develop Initial and on-going profile for individuals with ASD through comprehensive assessment focused on strengths and needs

2. Develop, recruit and retain people with expertise in working with individuals with ASD across relevant professions
3. Provide structured learning environments comprehensible to individuals with ASD
4. Provide well coordinated services and service plans
5. Develop best practice guidelines for allied health professional (medical/dental professionals-incl. EMTs, police, community helpers, etc.)
6. Once developed programs need monitoring continuously to make modifications on an ongoing basis.

Core practices recommendations:

1. Services to begin as early as possible

2. A minimum 25 hr/wk of individualized support, 12 months per year based on needs/ age of the individual

3. Meaningful, **functional**, and developmentally appropriate communication system for all individuals with ASD

4. Repeated, planned opportunities for socialization and to practice new skills

5. Constantly measure effectiveness and monitor progress

6. Build a centralized team to include

    family case manager

    resource coordinator

    all service providers using a collaborative model

7. Develop system to manage on-going personnel recruitment and retention

7. Create more mentorship/apprenticeship programs specific to ASD to develop a more knowledgeable base of providers

CHALLENGES:

1) Transition Challenges:

1. lack of communication amongst agencies throughout the lifespan

2. funding streams

3. lack of clearly defined roles and responsibilities

4. number and frequency of transitions

2) Medical/Mental Health Challenges

1. Primary Care Provider unaware of early signs and/or appropriate tools

2. Lack of diagnosticians

3. Confusion around terms of diagnosis

4. Health care providers lack knowledge and skills appropriate in working with children and adults with ASD

5. Health care providers lack knowledge about co-morbid conditions common to ASD diagnosis

6. Lack of health insurance

7. Lack of patient advocates with knowledge of ASD

3) Educational/Vocational Challenges

1. Lack of individualized curriculum and placement

2. Untrained, underpaid staff and high turnover rates

3. Lack of social skills education

4. Lack of vocational staffing and lack of assistance for employers

5. Lack of coordination and integrations across settings

6. Lack of self advocacy skill training

7. Lack of education towards lifelong independence

8. Lack of knowledge about appropriate inclusion

9. Lack of array of program options

10. Lack of accessibility to appropriate transportation

11. Lack of social curriculum, including health, sexuality, social safety, drug awareness, personal safety, bullying, etc

12. Lack of training for public safety personnel

13. Lack of meaningful jobs and support

14. Lack of post-secondary preparation and school supports

4) Recreation, Leisure and Community

1. Lack of supported accessibility to recreation, leisure and community opportunities

2. Lack of a range of appropriate programs

3. Lack of social opportunities

4. Lack of after school activities

5. Lack of a range of appropriate housing

6. Lack of understanding in the community of ASD

Recommendations:

Create best practice guidelines for a system of lifelong care.

Develop an "Umbrella Service Coordinator" to work with the family through the individual's entire lifespan.

A STRUCTURAL FRAMEWORK FOR IMPLEMENTAION OF "BEST PRACTICE" NEEDS TO INCLUDE:

1) Centralized family case manager to include:
   - Resource coordinator across lifespan and system
   - "ASD navigator"
   - State-funded individual

2) Centralized agency that:
   - Will eliminate duplicated services
   - Streamline number of meetings
   - Support collaborated model
   - Provide ongoing recruitment, training and retention of professionals

Practice Committee Back-up Documents

The New Hampshire Task Force on Autism, Part One

Assessment and Interventions

November 2001

www.autism-society-nh.org/atf.pdf

State of New Hampshire

Department of Health and Human Services

Division of Developmental Services

In Collaboration with Other State and Local Agencies, Private Providers, and Families

Educating Children with Autism

National Research Council

National Academy Press, Washington, DC 2001

The Puzzle of Autism

National Education Association

NEA Professional Library, Washington, DC 2006

www.nea.org/specialed/images/autismpuzzle.pdf

Autistic Spectrum Disorder Service Guide 1

Intervention guidance for service providers and families of young children with autistic

spectrum disorder, July 2002, Connecticut Birth to Three System, Hartford Connecticut

www.birth23.org/Publications/Autism2002.pdf

Caring for Washington Individuals with Autism, December 2006

Department of Health, Washington

www.doh.wa.gov/cfh/mch/Autism/documents/Autism_rep/ExecutiveSumm1-11-07.pdf

Effective Educational Practices for Students with Autism Spectrum Disorders

Focus on Autism and Other Developmental Disabilities

Volume 18, Number 3, Fall 2003

Rose Ivoannone, Glen Dunlap, Heather Huber, Don Kincaid

Best Practices for Serving Adults with Autism

Results of the study on services and supports for adults on the autism spectrum across the United States, Full Research Report

Prepared by: Autism Society of Delaware, Wilmington, DE

2004

www.delautism.org/best_practices_adults.htm

Pennsylvania Autism Task Force Executive Summary

December 2004

www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTask Force/003671610.htm

Autism Spectrum Disorders (ASD) Roadmap

Presenting to Interagency Autism Coordinating Committee

May 16, 2005

Contracted through Social & Scientific Systems, Silver Spring, Maryland

www.aucd.org/docs/policy/autism/autism_roadmap_asd.services_071305.doc

Vermont Interagency White Paper on Autism Spectrum Disorders

Agency of Human Services and Department of Education

March 2006

The Autism Task Force

http://autismtaskforce.com/downloads/best_practice_guidelines_screening_diagnosis_autism_young_children_may_2006.pdf

Taking Responsibility Good practice guidelines

 for services– adults with Asperger syndrome

Andrew Powell

The National Autistic Society